

# Chapter 9 – New South Wales



## Overview of palliative care in New South Wales

This section provides an overview of the context, structure, planning, delivery and monitoring of palliative care services in New South Wales (NSW).

### Recent history and context in NSW

The NSW Palliative Care Framework (the Framework) was published by NSW Health in March 2001 to guide the planning of comprehensive palliative care service delivery across the State. This followed a draft policy (May 1999) and a series of stakeholder consultations. Prior to that, NSW had published *Guidelines for Development of Palliative Care Services in NSW – Discussion Paper* (1985), *Report of the NSW Health Palliative Care Working Party* (1993) and *NSW Health Palliative Care Outcomes Workshop Report* (1994).

As such, the Framework had its origins prior to the National Palliative Care Strategy, but the final Framework embraced the National Strategy and recognised the growth in palliative care as a relatively new specialty area.

NSW was a party to the National Strategy, which was launched in October 2000 as a commitment of the Australian, State and Territory governments (along with other stakeholders) to the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and to the delivery of quality palliative care that is accessible to all people who are dying.

The Framework required each Area Health Service (AHS) to develop a three-year palliative care service plan. In May 2003, the Palliative Care Association of NSW reported to NSW Health on a review of the service plans. (Note that the overview was developed from plans as submitted. Services were not contacted to validate information or provide missing information.) The *Overview of Palliative Care Service Plans of NSW Area Health Services* (the Overview Report) was commissioned by NSW Health in order to provide:

- Feedback to the AHSs about their plans, comparative data, and information that may help improve planning and service delivery
- A statewide overview of progress with implementation of the Framework
- Information to assist the (then newly established) NSW Palliative Care Advisory Group (PCAG) to identify priorities for action and advise on strategies to achieve priorities.

Between June and August 2004, seven workshops were held with 137 participants to consult on the Overview Report and the local service plans, highlight achievements and identify ongoing service development needs. The three major areas of service need identified through the workshops were education and support for palliative care providers, ways to involve and upskill GPs in palliative care, and equity of access to services, especially in rural areas and aged care facilities.

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The PCAG has now developed a workplan which has in part been informed by the Overview Report. The PCAG reported on progress with the workplan at the annual statewide palliative care workshop (October 2004).

### Current arrangements in NSW

#### Introduction

Responsibility for palliative care policy sits within the Primary Health and Community Partnerships Branch of the NSW Department of Health.

The Framework has a series of principles which underpin the delivery of palliative care in NSW (Objectives 2.2, 3.1):

1. The patient and his or her carers are the focus of care.
2. Palliative care is provided in a setting appropriate to the patient and family needs and wishes.
3. Palliative care is provided in a culturally appropriate way to accommodate the needs of all patients who require care.
4. Service provision should reflect that palliative care can be required by children and young people as well as adults.
5. Early access to services that embody the concepts and principles of palliative care impacts significantly upon the wellbeing and quality of life of the patient.
6. Access to the range of specialised disciplines is required to meet the complex needs of the palliative care patient and their family.
7. Access to high quality clinical consultation for health care workers and a well-developed referral network is essential to high quality clinical care.
8. High quality palliative care includes a focus on bereavement support/follow-up for the patient and his or her partner, family, friends and informal and formal carers.
9. Education for the patient and his or her partner, family and carers throughout the continuum of palliative care is an important element of high quality care.
10. Education for GPs and other clinicians, as well as the wider community regarding the role and availability of the palliative care service in the area, is an important aspect of the service role.
11. Identification of the characteristics of clients, services and service outcomes provides a basis for improving the quality and effectiveness of service delivery.

#### Funding (Objective 2.2)

Funding for palliative care in NSW is principally provided from the global health budget provided to each AHS. Funding for palliative care service delivery is enhanced by funding provided to the States and Territories through the 2003–2008 Australian Health Care Agreements. In the 2003/04 financial year, NSW Health provided \$4 million in funding quarantined for palliative care, in addition to the global health funds provided to AHSs. The Australian Health Care Agreements provided \$11.4 million to NSW for palliative care services. The \$15 million in quarantined funds is primarily allocated to the AHSs using the NSW Resource Distribution Formula. However:

- 2% is allocated to support the Palliative Care Association of NSW, the Motor Neurone Disease Association, the Sydney Adventist Hospital and the Cancer Patients' Assistance Society
- Some funding is provided to other NGOs, but these allocations are made at the AHS level, and

Note that in Chapters 7–15, reference is made, where relevant, to numbered Objectives of the National Strategy. The Objectives are presented in full in Chapter 3.

- Some funding is provided to the two tertiary paediatric palliative care services – the Children’s Hospital at Westmead and the Sydney Children’s Hospital.

NSW also recognises the major contribution provided to some palliative care services by donations, charitable trusts and foundations (e.g. see ‘Key relationships with specific population groups in NSW’ on page 83).

Other funding for research and time-limited projects is reported in ‘Palliative care activity in New South Wales’ (page 88) and ‘Commentary about New South Wales’ (page 97).

#### **Service delivery structure** (Objectives 2.4, 3.2)

NSW Health is currently being restructured from 17 AHSs to eight AHSs and three statewide services. Each of the services has one or more identifiable palliative care services.

There is enormous structural diversity among palliative care services across the various AHSs. Some do not have a Medical Director of Palliative Care; some services (e.g. in rural areas) have no allied health or other non-medical non-nursing staff as team members. Service provision ranges from a major hospital setting through to part-time peripatetic community nurses. There appear to be three broad types of AHS palliative care models which operate in various settings of care (see also ‘Key relationships with specific population groups in NSW’ on page 83):<sup>5</sup>

1. Generalist Primary Care (community and nursing based; limited non-dedicated or contracted specialist support and inpatient beds available)
2. Specialist Consultation (limited direct care in dedicated inpatient beds with specialist care provided in partnership with generalist services and an interdisciplinary team available in both inpatient and community settings)
3. Specialist Direct Care (full dedicated multidisciplinary team in community and inpatient settings; services provided in parallel with generalist services; consultation services in community and acute care settings and dedicated inpatient beds in hospice/palliative care units).

Among these models, variation exists in referral pathways, networks and relationships with other services, availability and use of multidisciplinary team resources and the specific types of care provided in the different services.

#### **Note re volunteers**

The use of volunteers is not uniform across all AHSs. There is a NSW Co-ordinators of Palliative Care Volunteer Services Group (see ‘Key links with other strategies and frameworks in NSW’ on page 86).

#### **Equipment** (Objectives 2.2, 2.4)

The contribution of the national Palliative Care Equipment Program is being co-ordinated in NSW by the Palliative Care Association (see further details in ‘Palliative care activity in New South Wales’ on page 88).

## **Planned arrangements in NSW**

Prior to July 2004, NSW Health services were organised into 17 AHSs and three statewide services – namely the Children’s Hospital at Westmead, Justice Health and the Ambulance Service.

NSW Health has recently been restructured into eight AHSs and three statewide services, and there will be accompanying changes in the structure of palliative care services.

5. *An Overview of the Palliative Care Service Plans of NSW Area Health Services*, May 2003.

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### Planning, data collection, monitoring and reporting in NSW

#### **Planning** (Objectives 2.2, 2.4)

The Framework required each AHS to develop a three-year service plan. This planning at the AHS/regional level is complemented by statewide planning through an annual workshop of the NSW Palliative Care Advisory Group.

#### **Data collection** (Objectives 2.1, 2.2, 2.3)

While there is a nationally agreed minimum dataset for admitted palliative care patients, there is no agreed national or State minimum dataset for community-based palliative care.

Most AHSs currently collect data on inpatient-based occasions of care using AN-SNAP; however AN-SNAP is not widely used to capture community-based or outpatient care. A number of services have developed local data systems, predominately clinical databases that capture information about patients registered with a specialist palliative care service. The Community Health Information Management Enterprise (CHIME) software is being rolled out across all community-based health services. See <http://internal.health.nsw.gov.au/iasd/chime/> for more information.

#### **Monitoring and advice – NSW Palliative Care Advisory Group (PCAG)** (Objectives 2.2, 2.3, 3.1, 3.2)

The establishment of the PCAG was a recommendation arising from the review of AHS service plans (May 2003). It brings together a wide body of stakeholders in palliative care to provide expert advice to NSW Health on strategic directions and issues relating to palliative care. Members are representatives of:

- Palliative Care Association of NSW
- Palliative care service providers (nursing, medical, allied health, paediatric, volunteer, bereavement)
- NSW Society of Palliative Medicine
- NSW Cancer Institute
- Australia and New Zealand Society of Palliative Medicine
- Academics (University of Newcastle; University of Technology, Sydney)
- Australian Nursing Homes and Extended Care Association
- Carers NSW
- Health Participation Council
- General practitioners
- NSW Health representatives (The Director, Primary Health and Community Partnerships is co-chair).

The PCAG meets quarterly (following the inaugural meeting in September 2003) and has a workplan for 2003/04–2004/05 covering 14 major areas, largely arising from the 2003 review of AHS service plans.

Since that time, a Directors/Managers of Palliative Care Services Group has been established, operating independently from NSW Health.

#### **Reporting**

The PCAG presents annually at the statewide palliative care workshop. Its workplan is available on the NSW Palliative Care Program's website ([www.nsw.health.gov.au/pallcare](http://www.nsw.health.gov.au/pallcare)).

## Key settings of care in NSW (Objectives 1.3, 2.4, 3.1)

There are four settings of care identified in the National Strategy: home, community settings, inpatient palliative care beds and units, and acute hospital care. The following describes the NSW approach to these settings.

### Home and community-based care

All the palliative care models in the AHSs incorporate home/community-based care (see 'Current arrangements in NSW' on page 80).

There is also a range of local palliative care support services run by NGOs which are supported through the NSW Health NGO Grant Program, which is administered at an AHS level. Under this program, local NGOs receive funding for the provision of a wide variety of services to the community, including some with a palliative care focus. All services funded must operate in line with the *NSW Health Operational Guidelines for Non-Government Organisations*.

### Inpatient palliative care beds

Palliative Care Australia recommends 6.7 designated palliative care beds per 100,000 population. Currently, the distribution of specialist or dedicated beds is uneven across NSW, in both rural and metropolitan AHSs.

With respect to rural AHSs, all four have access to dedicated beds in a rural hospital and health service and three have access to dedicated beds in acute facilities.

All metropolitan AHSs have access to specialist inpatient palliative care beds in a specialist unit, and palliative care patients also occupy acute care beds in both metropolitan and rural areas.

### Hospice services

Historically, there have been a number of hospice facilities in NSW run by religious or charitable organisations. Their location has, to some extent, been determined more by historical developments than by any other demand factors. These hospice services offer both inpatient and day hospice services. See the note re the children's hospice in 'Key relationships with specific population groups in NSW' below.

### Note re respite care

In NSW, inpatient and day respite is provided through inpatient palliative care beds or units and hospices. The Commonwealth Carer Respite Centres (CCRCs), funded across Australia through the Ageing and Aged Care Division of the Department, provide information, referral, access and co-ordination of respite services (including in relation to palliative care). In 2003, specific funding for palliative care (nationally \$11 million over four years) was added to the 'brokerage component' of CCRCs, requiring that 6% of brokerage money be spent specifically on respite related to palliative care. NSW has 18 such CCRCs.

## Key relationships with specific population groups in NSW (Objectives 2.4, 3.2)

A number of different population groups are identified in the National Strategy. The focus of palliative care in NSW includes people with cancer as well as non-cancer diagnoses such as HIV/AIDS, progressive neurological conditions and end-stage organ failure. The current approach to some particular groups is as follows.

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### **Aged care**

The PCAG workplan includes action to identify the support provided by specialist palliative care services to aged care facilities and the palliative care services which are needed. Consideration will also be given to the *Guidelines for a Palliative Approach in Residential Aged Care* (a national initiative funded by the National Palliative Care Program).

Currently, specialist palliative care services provide some advice, consultancy services and education to residential aged care facilities. In the Hunter AHS, for example, palliative care liaison nurse positions have been established, based on a model in South Australia. Education days have been provided to enrolled nurses, assistants in nursing and registered nurses – and these opportunities have had strong attendance.

The Alzheimer's Association (NSW) runs a one-day course called Palliative Care in Dementia.

### **Children and young people**

Currently NSW has two tertiary paediatric palliative care centres – the Children's Hospital at Westmead and Sydney Children's Hospital – providing statewide paediatric palliative care services. Both services are multidisciplinary (specialist medical, nursing, social work and bereavement support) and both provide consultancy-based care to inpatients and advice to health professionals across the State who are providing care to dying children.

The PCAG workplan includes action to survey paediatricians and adult palliative care services to determine their support needs in caring for children with a life-limiting illness.

The State's first children's hospice, Bear Cottage, at Manly, was opened in March 2001. It is the first children's hospice in the world to be owned and operated by a children's hospital. The hospice provides palliative and respite care for children with terminal and life-limiting illnesses and their families, as well as bereavement support. There are ten bedrooms.

Paediatric palliative care aims to maximise the quality of life of the child with a life-limiting illness and to provide support to the child's family and other carers. It is estimated that 1 in 10,000 children have a life-limiting illness. The sources of patients for Bear Cottage are 30% from the Children's Hospital at Westmead, 30% from Sydney Children's Hospital, 10% from John Hunter Children's Hospital and 30% from elsewhere.

At a cost of \$7.9 million, the establishment of Bear Cottage has been entirely funded through community donations. Operational costs of an estimated \$1.5 million per year are also funded from donations, with some funding support from the NSW Department of Health.

### **Aboriginal and Torres Strait Islander peoples**

Aboriginal and Torres Strait Islander people are under-represented in the utilisation of palliative care services in NSW.

The Mercy Health Service in Albury has been participating in the project team at Wodonga developing an *Indigenous Palliative Care Resource Kit* (a national initiative through the National Palliative Care Program).

A number of AHSs have strategies to specifically promote access for people of Indigenous or culturally diverse backgrounds in their palliative care service plans. For example, in Wentworth Area Health Service (WAHS), an Aboriginal palliative care project officer has been appointed to develop culturally sensitive palliative care resources for Aboriginal communities within WAHS (funded under the Caring Communities Program, a national initiative through the National Palliative Care Program).

NSW Health is also implementing the *Providing Culturally Appropriate Care to Indigenous Australians Resource Kit*, also developed under the National Palliative Care Program.

### **People with specific cultural and linguistic needs**

WAHS has undertaken a project called Palliative Care for a Diverse Community, and the PCAG workplan includes action to consider the findings from this project. The project aimed to enhance the provision of appropriate and responsive palliative care services to people from culturally and linguistically diverse backgrounds within WAHS and, among other outcomes, produced patient information pamphlets in a number of community languages.

### **People with cancer**

People with cancer are said to constitute 85–90% of adult palliative care referrals in NSW.<sup>6</sup> NSW has both the NSW Cancer Council and the newly established NSW Cancer Institute.

The NSW Cancer Institute was established in June 2003 under State legislation with a budget of \$205 million over four years. Its objectives include improving the quality of life of cancer patients and their carers. It has assumed a number of functions from the Cancer Council, including the Central Cancer Registry. The minimum dataset for the registry includes two palliative care items. While it is not envisaged that the Cancer Institute will provide recurrent funding, 50 new cancer nurse positions have been created under the Cancer Nurses Program, of which six are specifically for palliative care nurses. The Cancer Institute has a significant cancer research program (25% of its budget) and it is likely that some research initiatives could be undertaken in the area of palliative care.

### **People with HIV/AIDS**

The AIDS Dementia and HIV Psychiatric Service (ADAHPS) is a statewide tertiary service of NSW Health for people with AIDS dementia complex and HIV-related psychiatric conditions. It is jointly auspiced by South Eastern Sydney Area Health Service (SESAHS) and Central Sydney Area Health Service (CSAHS). The service includes The Bridge, an external facility of Royal Prince Alfred Hospital which is Australia's first residential care service for people living with AIDS dementia complex and associated conditions. It is located in the inner Sydney suburb of Glebe and was opened in January 1998. The Bridge provides supervised and supported accommodation for up to 12 people (long-term residential, short-term rehabilitation, and pre-planned respite). Care is provided 24 hours a day by an experienced team of staff. Palliative care is offered to those residents who:

- Need assistance and ongoing management of pain and other symptoms
- Need care and support facing progressive and/or terminal stage of their disease.

The CSAHS on-call Palliative Care Service will provide 24-hour cover in a consultative manner, with nursing after-hours visits if required and medical telephone back-up for people with HIV/AIDS in the community.

Sacred Heart and its associated community outreach palliative care service is a major provider of palliative care to people living with HIV/AIDS.

### **Activities in rural and regional NSW**

The NSW Rural Palliative Care Nurses Group held its first annual meeting in western NSW in 1990. Its initial focus was primarily to directly support palliative care nurses. Early activities included preparing teaching packages, sharing resource development and peer support. The group has support from NSW Health, Palliative Care Australia and the Palliative Care Association of NSW.

6. *NSW Palliative Care Framework 2001.*

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At the Lightning Ridge meeting in 2004, the group refocused its objectives to:

- Advocate for rural palliative care
- Review clinical practice in palliative care in rural and remote NSW
- Maintain professional networks within rural and remote palliative care services
- Promote education relating to palliative care across rural and remote NSW using the combined knowledge of group members
- Support research which promotes best practice in rural and remote palliative care
- Provide peer support to members.

The group has recently produced position papers on access to Home and Community Care (HACC) services and staffing levels in rural areas and has developed a survey on how home deaths are managed. The group is working on a position paper on problems with accommodation and travel for people from remote and rural areas who must travel for treatment, and on scoping papers on allied health support and specialist medical support.

The group has identified that maintaining volunteers in rural and remote areas is difficult for a number of reasons, including travel costs and time involved in training, together with inconsistent work affecting maintenance of confidence in their skills. The structure of HACC services makes it difficult to respond swiftly to hospital discharge for palliative care.

### Carers

The PCAG workplan includes action to identify consumer and carer expectations of palliative care and understanding carers' needs for information, education and support. It is proposed that this work be undertaken by survey.

### Key links with other strategies and frameworks in NSW (Objectives 3.1, 3.2)

One of the features of palliative care services in NSW is the provision of palliative care as an integral part of other health and support services. In addition to the NSW Framework, there are some other key strategies and operational frameworks in NSW which influence palliative care planning and practice:

- Palliative Care Advisory Group
- Palliative Care Association of NSW
- NSW Rural Palliative Care Nurses Group
- Cancer Council of NSW
- NSW Cancer Institute (and its NSW Cancer Plan)
- NSW Co-ordinators of Palliative Care Volunteer Services Group
- NSW Chronic Care Program
- A number of professional workforce groups specific to palliative care.

### NSW Co-ordinators of Palliative Care Volunteer Services Group (Objective 3.1)

This group was formed in 1992. Meeting quarterly, it provides an opportunity for co-ordinators of volunteer palliative care services to meet and share information about work, provide support for each other as well as support professional development, including raising the professional profile of volunteers. Where appropriate, guest speaker/resource people are invited to the meetings to discuss specific issues. The convener position has a term of two years which rotates among co-ordinators.

Functions of the group include:

- To network, support and exchange current information pertaining to service delivery
- To communicate and exchange ideas on issues related to funding, government guidelines, occupational health and safety, selection and recruitment and conflict resolution
- To offer an opportunity for co-ordinators to network, develop and exchange strategies to deal with arising situations involving volunteers, clients and various health professionals/community groups
- To work on joint projects (e.g. development of policies/procedures manual)
- To inform members of opportunities for professional development and education.

#### **Occupational Therapy Oncology and Palliative Care Focus Group** (Objectives 1.3, 1.4)

This group is an official focus group of OT Australia NSW. The group meets quarterly at the Independent Living Centre in Ryde. The general principles of the focus group are:

- To provide a support system for occupational therapists interested in the area of oncology and palliative care
- To support research and continuing education programs in the areas of oncology and palliative care
- To respond to relevant documents/policies/literature on behalf of OT Australia NSW
- To discuss political and industrial issues with OT Australia NSW which are affecting the profession
- To facilitate evidence-based practice in current occupational therapy practice within the areas of oncology and palliative care
- To encourage the highest standards of ethical conduct in the practice of occupational therapy.

#### **Palliative Care Social Workers** (Objectives 1.3, 1.4)

This group began in 1996 and became formally recognised by the Australian Association of Social Workers in July 1998. Membership is open to social workers eligible for membership of the Australian Association of Social Workers who work with palliative care patients in hospice, community and hospital settings. Meetings are hosted three times a year in March, July and November, with rotating venue and chairperson. The objectives are:

- Exchange and dissemination of information
- Forum for interchange of ideas
- Professional support and stimulus
- Professional education specific to areas of practice, including clinical presentations
- Advocacy option for relevant issues.

#### **Physiotherapy in Palliative Care Special Interest Group** (Objectives 1.3, 1.4)

This group is open to any physiotherapist working in, or with an interest in, the area of palliative care. Currently the group meets three to four times per year, with responsibility for co-ordination being 'handed on'. The aim of this group is to promote and develop the quality of physiotherapy care to palliative care and oncology patients. Specific objectives include:

- To promote and develop the role of physiotherapists working in palliative care and oncology to the profession and other health disciplines
- To provide a forum to facilitate communication between physiotherapists working in palliative care and oncology
- To provide a forum for education for physiotherapists working in palliative care and oncology.

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### **The Cancer Plan 2004–2006** (Objectives 3.1, 3.2)

This plan has built on a number of initiatives, including the August 2003 NSW Health Clinical Service Framework for Optimising Cancer Care in NSW, and has as its central philosophy a patient-centred approach. The Framework has identified seven standards to be at the core of any patient-centred, best practice cancer service; these have been supported in the NSW Cancer Plan. They included, among other items, access to appropriate clinical services.

Standard 4.7 of the Cancer Plan states: ‘Protocols and strategies are in place to ensure access to specialist palliative care services for patients with advanced cancer (by June 2004)’.

The Cancer Plan states at Goal 19 (under ‘Special issues in cancer care’):

Provide cancer patients with early and appropriate access to palliative care services

19.1 The integrated palliative care program

19.2 Palliative radiotherapy review.

The Cancer Plan also includes a program relating to workforce review, including the palliative care workforce. Under this program, funding is provided for registrar training positions.

### **The NSW Chronic Care Program** (Objectives 3.1, 3.2)

This program includes a number of clinical services frameworks, including the Framework for Optimising Cancer Care in NSW, which has been extended through the NSW Cancer Plan (discussed above), the Clinical Service Framework for Heart Failure, and the Clinical Service Framework for Chronic Respiratory Disease.

The Clinical Service Framework for Heart Failure includes the following standard (Standard 9) for palliative care for patients with end-stage heart failure:

All AHSs should ensure that patients with intractable chronic heart failure (CHF) have access to appropriate palliative care services.

The target date set for this standard is June 2005 and includes not only access to palliative care services but also having protocols in place for the appropriate management of CHF patients.

## **Palliative care activity in New South Wales**

This section provides additional information about projects, research, initiatives and influences in the broader palliative care sector in NSW.

### **Reform, training and research in NSW**

There is a range of reform, training and research initiatives which have occurred, or are occurring, in NSW. Some are funded through the National Palliative Care Program but are being conducted in NSW; some are funded by NSW Health; others arise through various grant and research arrangements.

There is variety of projects and research activities at the local AHS level which have not all been identified within this report. (Examples are the information video *A Cry for Help*, designed to target the broad community in order to inform them about services available, funded through a partnership between the Blue Mountains Palliative Care Volunteers and WAHS; the research project *Palliative Care Dementia Interface: Enhancing Community Capacity*, undertaken by Prof Esther Chang, Ms Kathleen Harrison and Dr Michael Noel, also in WAHS).

Some of the more significant initiatives in NSW are described below.

### **National Contribution to NSW Reform in Palliative Care** (Objective 2.4)

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The Australian Government, through the National Palliative Care Program, has offered funding to assist each of the States and Territories to undertake strategic activities that would progress the reform agenda in palliative care and support the policy, Goals and Objectives of the National Strategy. An amount of approximately \$100,000 was allocated to NSW and this has funded a major project to develop a role delineation framework for palliative care services, together with the consultation activities associated with the overview of the AHS palliative care service plans. A two-tier framework is proposed:

- Working Together Framework – a partnership framework for primary care and specialist services who provide care for people with life-limiting illness, and
- Resource and Capability Framework for Specialist Palliative Care Services – a three-level framework for organising specialist palliative care services on the basis of their available/planned resources and expected capabilities and role.

Status	Current project. The role delineation framework will be validated in 2005
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### **Program of Experience in the Palliative Approach (PEPA)** (Objectives 1.3, 1.4)

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This program is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The National Palliative Care Program has made funding available for PEPA, which provides primary health care practitioners with an opportunity to develop skills in the palliative care approach by undertaking a short and flexible program of planned work placement with a metropolitan or larger rural specialist palliative care service.

The PEPA program in NSW has a budget of \$855,000. The first round of PEPA placed 63 participants; 80% were nurses and 20% were allied health, while 73% were from rural NSW and 27% from metropolitan NSW. Including second round applications, a further 179 applicants are awaiting placement in 2005/06.

Status	Funding available till June 2006
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Evaluation	Nationally co-ordinated
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Reports, information, materials	See website for materials: <a href="http://www.health.nsw.gov.au/pallcare">www.health.nsw.gov.au/pallcare</a>
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### **Rural Palliative Care Program** (Objectives 1.4, 2.2, 2.5, 3.1, 3.2)

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The Rural Palliative Care Program is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The National Palliative Care Program has made funding available over a three-year period to support eight Divisions of General Practice across Australia in the development and implementation of collaborative models, demonstrating improved access to multidisciplinary care for rural communities. In NSW, two Divisions of General Practice are participating. They are the Mid North Coast and SE NSW Divisions of General Practice. Services commenced operating on 31 August 2004.

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At the Mid North Coast, there has been an emphasis on palliative care ‘Link Nurse’ education (particularly for residential aged care facilities); a ‘virtual’ palliative care team involving private, public, acute and community team members; and use of PalCIS via Palm Pilots to gather patient data. At SE NSW (Eurobodalla) the project has developed an after-hours on-call service and there has been an emphasis on training and information (e.g. fact sheets for health professionals, a resource directory, broader ideas for families).

Status Ongoing

Evaluation Yes

Reports, information, materials Further information at [www.adgp.com.au](http://www.adgp.com.au)

### **Palliative Care Equipment Program** (Objectives 2.2, 2.4)

The Palliative Care Equipment Program (\$3.8 million over two years) is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The initiative (being administered through Palliative Care Australia) provides grants to organisations in each State and Territory for the purchase of equipment that can be loaned to families and carers of people receiving palliative care at home, particularly organisations in rural or remote communities or those with links to residential aged care facilities. In NSW in 2003 and 2004 almost \$1 million was made available for the purchase of palliative care equipment. The program was administered by the Palliative Care Association of NSW.

Status Completed

Reports, information, materials The Palliative Care Association of NSW provides reports to Palliative Care Australia, and reported to the National Palliative Care Program in October 2003

### **The Griffith Area Palliative Care Service (the GAPS project)** (Objectives 2.4, 2.5, 3.1)

Commencing in October 2001, the Griffith Area Palliative Care Service (GAPS) project was funded as a demonstration project through the National Palliative Care Program. At a broad level, it aimed to assess how the National Strategy could be translated into a model of care that is appropriate and sustainable for rural Australia. The project aimed locally to improve palliative care services for residents in the Western Riverina region, starting in Griffith (approx 20,000 residents) and later being extended to residents in the surrounding areas of Coleambally, Darlington Point, Hay and Hillston. The final evaluation was published in May 2003, and noted that where specialist palliative care service is not a realistic option for small, dispersed communities, the GAPS model, with its primary care and multidisciplinary approach, is a quality alternative.<sup>7</sup>

Status The findings of this project have now been extended to a larger trial through the Rural Palliative Care Program

Evaluation See below

Reports, information, materials Owen A, Perkins D, Senior K and Eagar K (2001) *The Griffith Area Palliative Care Service: A Baseline Assessment of its Evaluability*,

7. Cromwell D, Senior K, Owen A, Gordon R and Eagar K (2003), p iv.

*Sustainability and Generalisability*, Centre for Health Service Development, University of Wollongong  
 Owen A, Perkins D, Senior K, Cromwell D, Eagar K and Gordon R (2002)

*The Griffith Area Palliative Care Service: Second Evaluation Report*, Centre for Health Service Development, University of Wollongong  
 Cromwell D, Senior K, Owen A, Gordon R, and Eagar K (2003) *Can the National Palliative Care Strategy be Translated into a Model of Care that works for Rural Australia? An Answer from the Griffith Area Palliative Care Service (GAPS) Experience*, Centre for Health Service Development, University of Wollongong

### NSW Health Seed-funded Projects

The workshops held between June and August 2004 to discuss the AHS palliative care plans generated further priority-setting within each of the AHSs. This has led to the development of a number of priority projects in each AHS which have been seed-funded by NSW Health. A total of \$370,000 has been allocated to these projects, on the basis of \$20,000 per AHS and \$10,000 to each of Sydney Children's Hospital, Children's Hospital at Westmead and Justice Health. These projects are listed in the table below (including reference to the related Objective in the National Strategy).

Area Health Service/hospital	Project
Hunter (Objective 2.5)	To develop consistent referral criteria for Hunter palliative care services To identify factors that lead to inequitable access to 24/7 palliative care services and to identify resource issues that impact on the ability to provide timely visits to clients in rural and outer metro areas
Northern Sydney (Objective 2.5)	To identify what is the target palliative care population in North Sydney AHS (NSAHS) To identify all services involved in end-of-life care in NSAHS, including community-based support services To develop a set of standardised assessment and referral documentation To ensure data collection against standards To assess the education needs of staff involved in the care of palliative care clients (specialist and generalist) To map all current care providers, and develop and distribute a palliative care service directory (including web-based)
Northern Rivers (Objective 1.4)	To develop a training package to meet the palliative care needs of the local Aboriginal community To develop information material for clients, including Aboriginal clients To establish a bereavement library in each of the three palliative care services
Central Sydney (Objective 3.2)	To develop a GP consultation process To develop and run workshops for staff on teamwork, burnout and bereavement

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Illawarra (Objective 3.2)	To develop the role of palliative care services in residential aged care facilities
South Western Sydney (Objective 1.4)	To strengthen engagement and communication with GPs, Divisions of General Practice and pharmacists through one-day workshops
Macquarie (Objective 3.1)	To identify and adapt a clinical support package for primary health care providers To produce information on local palliative care services for the general community and health services
Children's Hospital at Westmead (Objective 3.1)	To establish a bereaved parent support group at Bear Cottage
Sydney Children's Hospital (Objective 3.1)	To develop a bereavement package that can be tailored to a family's needs To develop a Sydney Children's Hospital palliative care information brochure to raise awareness of services available
Western Sydney (Objective 2.3)	To purchase a palliative care database (PCS from SESAHS) and enter existing paper-based palliative care data
New England (Objective 1.4)	To ensure ongoing sustainability of community-based volunteer service and bereavement support through developing a training module to be included in general HACC and NALAG volunteer training and protocols for ongoing support and monitoring
Mid North Coast (Objective 2.4)	To establish an after-hours telephone support and advice service
Far West (Objective 2.3)	To develop area-wide standardised palliative care policies, procedures and documentation To enhance on-site and PEPA education through providing funding for additional educational opportunities To investigate the development of a community-owned volunteer bereavement training program
Mid Western (Objective 1.4)	To provide the Therapeutic Guidelines – Palliative Care to all health services To provide scholarships for formal palliative care nursing courses To provide hand-held computers to specialist palliative care nursing staff
Central Coast (Objective 2.3)	To develop a networked integrated information system

### **Palliative Care for a Diverse Community** (Objectives 1.1, 2.4)

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Wentworth Area Health Service (WAHS) undertook a project, Palliative Care for a Diverse Community, which aimed to enhance the provision of appropriate and responsive palliative care services to people from culturally and linguistically diverse backgrounds within WAHS. It was funded by NSW Health and the partners were the WAHS Palliative Services, Chronic and Complex Stream and Cultural Equity Unit. The project has also produced patient information pamphlets in a number of community languages.

Status	Completed
Evaluation	Information pamphlets in a number of community languages
Reports, information, materials	Draft report available

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### **Caring Communities Program projects in NSW** (Objective 1.1)

The National Palliative Care Program has provided one-off funding through the national Caring Communities Program for individual projects to improve the capacity of communities to care for someone with a life-limiting illness – specifically to improve the proportion of time that patients are cared for in the setting of their choice and to improve their satisfaction with care. Nine projects from NSW were successful in receiving funding.

### **Motor Neurone Disease Volunteer Visitors Pilot Program** (Objectives 1.1, 3.1)

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Conducted by the Motor Neurone Disease Association of NSW Inc, this project is developing and implementing a motor neurone disease (MND) volunteer visitor program to maximise quality of life for a person with MND, their family and their carer to enable them to continue to be cared for in the setting of their choice and to provide ongoing bereavement support for the carer and family for up to six months following death. A small number of volunteers have been placed with people in the terminal stages of MND. In addition, the project has run a number of training sessions which have given specific MND carer education to generic palliative care providers. Participants are provided with a manual for future reference.

Status	Ongoing to January 2006
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Major newspaper feature article <i>The Herald</i> Newcastle and Hunter, 23 March 2004 June 2004 MND Forum – The Newsletter of the MND Association of NSW contains a brief article on the training program for volunteer visitors See <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a>

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### **Predictors of Home Death in Residents of Central Sydney Area Health Service (CSAHS) Dying of Cancer** (Objectives 1.1, 1.2, 2.5)

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The aim of this project is to determine which of the following factors are causal for place of death in residents of CSAHS. Most people say that when the time comes they would prefer to die at home, but only a few achieve this goal. Many factors will determine the place of death. Surveys indicate an association between factors related to the patient, their disease and their care system and the place of death. The information from the project will sustainably improve individual patient care by identifying those factors that can be ameliorated within the available resources, such as varying the amount of professional support provided. The project has obtained ethics approval and is seeking ways to access recently bereaved families of cancer patients. A number of conference papers have been presented, both in Australia and Italy.

This project is being run by CSAHS.

Status	Ongoing to May 2006
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Conference papers: www.cpcrc.com – contains paper, <i>The Home Deaths Project</i> , presented at 3rd Annual Research Conference – Centre for Palliative Care Research and Education (Brisbane) <i>The Home Deaths Project</i> paper also presented at International Palliative Care Nursing Research Conference, Monash University, Melbourne, 7–11 June 2004

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### **Helping Communities Care: Volunteer and Bereavement Support Networks** (Objectives 1.1, 1.2, 2.5)

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This initiative aims to develop, pilot and evaluate sustainable context-specific community development model(s) for volunteer activities and bereavement support suitable for the diverse range of rural communities found in the Mid Western Area Health Service (MWAHS). A community development approach has been taken to develop enduring networks of volunteer activity and bereavement support mechanisms for individuals with life-threatening illnesses and their carers. The MWAHS and the Cancer Council formed a partnership to undertake the projects, harnessing the skills, knowledge and resources of each organisation and local MWAHS communities. Pilot networks were conducted in Grenfell, Lithgow and Bathurst.

This project is being undertaken by MWAHS.

Status	March 2004 – January 2006
Evaluation	Through the national cluster evaluation of the Caring Communities Program

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### **Kids' Grief: A Handbook for Group Leaders** (Objectives 1.1, 1.2, 1.4)

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The National Centre for Childhood Grief Australia Ltd produced a manual/handbook to enable skilled professionals and volunteers to conduct effective support groups for bereaved children. Although developed in Sydney, this practical, user-friendly resource is invaluable for use with children in remote areas and in health settings with limited resources and has potential application nationally. Workshops and conference presentations have been undertaken. Over 250 copies of the resource have been sold to date. The initial print run was 5,000.

Status	Completed
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	<i>Kids' Grief Handbook</i> is available for sale through the website of the National Centre for Childhood Grief, <a href="http://www.bereavementcare.com.au/default2.htm">www.bereavementcare.com.au/default2.htm</a>

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### **Palliative Care Education Utilising Interactive Satellite Television Technology** (Objectives 1.1, 1.2, 1.4)

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Conducted by Anglican Retirement Villages, this project used satellite television technology to develop four interactive palliative care education programs for workers in residential aged care facilities. The topics of the four programs were:

1. Palliative care overview
2. Death and dying
3. Pain management
4. Dealing with grief and loss.

Each of these four sessions was screened five times, with an interactive live panel at each session.

Status	Completed
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	There is a video copy of the interactive sessions. Availability of the video is unknown

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### **Supporting and Educating Carers in Palliative Care** (Objectives 1.1, 1.2, 1.4)

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Carers NSW, in partnership with two CCRCs (Illawarra and Central Coast), will provide face-to-face education and telephone follow-up support to carers of people who require palliative care. The education will comprise two components: 1) around the dying process and practical caring issues; and 2) psycho-education on grief, bereavement and coping with loss. The face-to-face education session runs 9.30am–3.30pm and leads the carer through information on palliative care, resources, loss and grief and coping skills, with the added benefits that come from a group of people with common problems and solutions. A number of newspaper articles have been published. The telephone follow-up will draw on Carers NSW's expertise in providing telephone group counselling. A small amount of primary health professional education will also take place.

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Status	There are four courses in the Illawarra area (Dapto, Nowra, Corrimal and Ulladulla), and six courses in the Gosford-Wyong area between May 2004 and March 2005.
Evaluation	Each course has three telephone group sessions as follow-up, to gauge change in carers' skills to deal with and understand their situation and to reinforce those skills. Evaluation will also be through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	See the Carers NSW website for more information on the project, <a href="http://www.carersnsw.asn.au">www.carersnsw.asn.au</a>

### **Developing Linkages between the Indigenous Population and a Palliative Care Service**

(Objectives 1.1, 1.2, 2.3)

An Indigenous palliative care liaison officer has been appointed to create sustainable links between the Indigenous population and a palliative care service, enhancing service delivery to Indigenous patients and their families. The liaison officer is a community elder, and to date a number of focus groups have been conducted to identify the needs of Indigenous patients. Results are being collated. This project is being undertaken by Wentworth Area Health Service (WAHS).

Status	Ongoing to April 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program

### **Palliative Care Dementia Interface: Enhancing Community Capacity** (Objectives 1.1, 1.2, 3.1)

This project aims to develop strong partnerships between community-based palliative care service providers, specialist aged care and dementia services and residential care facilities to facilitate optimal and sustainable palliative care service delivery for people with end-stage dementia.

It aims to facilitate and foster the cultural learning necessary within palliative care, aged and dementia health care professionals to appropriately address the needs of this client cohort, in a sustainable fashion within the broad community. A training module and documentation are under development, with a range of professional development activities to follow.

The project partners are University of Western Sydney, Wentworth Area Health Service (Chronic and Complex Care) and Blue Mountains Division of General Practice.

Status	Ongoing to May 2006
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	A number of conference presentations and journal articles have arisen from this project, such as the dementia palliative care interface – identifying the issues, understanding the needs of people dying from dementia, and the Hammond Care Conference – Dementia and Depression (Sydney) June 2004

### **Southern Area Health Service: Formalising Linkages with Bereavement Support** (Objectives 1.1, 1.2, 3.1)

This project aims to identify existing bereavement supports in Queanbeyan and the surrounding area and develop a community-based model to link services. It is planned to develop a resource library and a range of education sessions to resource bereavement support providers, including informal networks of support. Specific education and general supportive follow-up will be available.

Status June 2004 to May 2006

Evaluation Through the national cluster evaluation of the Caring Communities Program

### **The peak body – Palliative Care Association of NSW** (Objectives 1.1, 1.2, 1.3, 3.2)

The Palliative Care Association of NSW is recognised as the peak body in the State. It describes its role as follows: ‘The Association assists in the development of quality standards, lobbies the NSW government for equitable funding, conducts public awareness activities in National Palliative Care Week and is a referral service for people seeking information.’<sup>8</sup> The Association also publishes a quarterly journal, *Pallium*.

The Association was established in 1985/86 when palliative care was emerging as a separate discipline in NSW. Its membership is comprised largely of individual clinicians, with a focus on advocacy at the service level rather than consumer advocacy. The organisation is currently reviewing its constituency and considering whether this should include organisational membership.

The Association has strengthened relationships with NSW Health in recent years and this has been reflected in the following activities:

- The Association undertook a project which resulted in the May 2003 *Overview of the Palliative Care Service Plans of NSW Area Health Services* (Overview Report)
- There is a joint arrangement for implementation of the PEPA project, with the project co-ordinator working with the Association
- The Association has been contracted to undertake the Resource and Capability Framework for Specialist Palliative Care Services (Role Delineation) project
- The Association is a member of the NSW Palliative Care Advisory Group
- The Association runs an annual State conference.

8. [www.palliativecarensw.org.au/index.html](http://www.palliativecarensw.org.au/index.html)

### Commentary about New South Wales

This section provides a summary of the trends and influences emerging in palliative care in NSW. There is a commitment in NSW by the Primary Health and Community Partnerships Branch of NSW Health to consult with and involve the sector and advocate on the palliative care sector's behalf to AHS management. The Palliative Care Advisory Group is an important structure and the Palliative Care Association of NSW is an important partner.

Drivers of development in the palliative care sector in NSW appear to be:

- **Definitional issues.** The Overview Report indicated that statewide service planning would require the underpinning of a common definition of a palliative care service and a palliative care patient
- **Standards.** Minimum standards for access to services by patients were needed which took into account the needs of specific groups within the community and were relevant to the needs of metropolitan and rural communities. The Role Delineation Project (Resource and Capability Framework) is contributing to this understanding, together with the Review of Standards for Palliative Care Services and Models of Care (a project being conducted at a national level by Palliative Care Australia)
- **Data sources.** The Overview Report indicated that there was no current data source which would provide information to allow comprehensive knowledge of service structures, practices and outcomes on a statewide basis
- **The NSW Palliative Care Advisory Group.**
- **The Annual Palliative Care Workshop.** This has now been running for three years and brings together representatives from NSW Health and NGOs involved in palliative care across NSW
- **The increasing numbers of patients with non-malignant diagnoses.** Services are very receptive to this cohort of patients but in many cases will need to reconfigure their service model.

#### Further information

[www.health.nsw.gov.au/pallcare](http://www.health.nsw.gov.au/pallcare)

*NSW Palliative Care Framework*, NSW Health, 2001

*NSW Cancer Plan 2004–2006*